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Mr. Chairman and members of the Committee, I am Myrl Weinberg, President of the National Health Council. I am very pleased to have the chance to testify today on the critical issue of caregiving and I commend the Committee for devoting such time and energy to raising awareness about this important issue.

To put my testimony in context, I would like to briefly describe the National Health Council. The Council is a private, nonprofit umbrella organization of more than 100 health-related organizations. The Council's core membership includes over 40 of the nation's leading voluntary health agencies, such as the American Cancer Society, Alzheimer's Association, Easter Seal Society and National Multiple Sclerosis Society. Other Council members include such organizations such as the National Family Caregivers Association, American Association of Retired Persons, American Medical Association, and private businesses such as Pfizer Inc., Amgen Inc. and Aetna U.S.

The Council's mission is to improve the health and well-being of those individuals with chronic diseases and/or disabilities.

As of 1995, there were nearly 100 million people in America with a chronic condition, according to a Robert Wood Johnson study, "Chronic Care in America: A 21st Century Challenge" (August 1996). And that number is growing as the population ages and as medical research continues to find ways to extend life. By 2020, it is projected that 134 million Americans will have at least one chronic condition. For example, the Arthritis Foundation estimates that by the year 2020 more than 60 million Americans, or 20% of the population, will suffer from arthritis.

As we have already heard today, most people with chronic diseases and/or disabilities receive care not only through the formal health care system, but also from family members or friends. In fact, these informal caregivers often are the first "line of defense" for persons with chronic diseases and/or disabilities, providing the majority of day-to-day assistance required. Surveys indicate that there are more than 22.4 million family caregivers in the United States - a three-fold increase over the last ten years. And, as previous speakers have already demonstrated, the financial value of caregiving is tremendous, accounting for approximately 20% percent of national health care expenditures or nearly \$200 billion annually.

The need for family caregiving is only going to increase with time, as will the financial implications of caregiving. Unless this informal system of care is supported, expanded and sustained through public policies, we will face a long-term care crisis, shifting demands and costs to both the public and private insurance markets. That is why today's hearing is so critical.

In order to avert a long-term care crisis, public policies should be adopted to support family caregivers and the services they require. A one-size-fits-all government-run program is probably not the solution, nor is it politically feasible at the current time. However, local, state and federal policies can do much to bolster and expand existing programs and create incentives within the health care system to meet the growing needs of caregivers and to meet future demands for caregiving services. The development of such public policies must be the basis for additional discussion and debate. There are three basic areas where caregivers require support. First, when the initial health care crisis occurs caregivers need information about the diagnosis and course of disease. They will need training about the medical treatments they will be expected to provide and administer to the care recipient, and acknowledgment

that they will be a key participant on the health care team. Second, caregivers need support to meet the day-to-day, long-term care needs of the care recipient. Families and friends willingly become caregivers, but respite care, and a blend of home care and other interventions are needed to provide additional supports. Furthermore, it is important that caregivers are prepared for the impact this role will have on their own lives. Guidance must be offered and a support system should be in place to prevent emotional and physical "burn-out" that can cause caregivers to become care recipients themselves. And, lastly, caregivers require financial support. One cause of great stress to caregivers is the financial insecurity that comes with a chronic or disabling illness requiring full time, long-term care.

I would like to spend just a few minutes on each of these areas. As I do, I will offer suggestions of some existing programs that can be expanded or improved, and will highlight some innovative programs that are working today.

First, support is needed when the initial health care crisis occurs, and continues throughout the crisis. Often, medical care must be provided in the home, such as giving injections and monitoring and maintaining medical equipment - care that once was provided solely by doctors and other health professionals. As fewer people are admitted to nursing homes and hospitals, and as hospital stays grow shorter, families and friends are taking on an unprecedented role in providing these medical services. Much of this shift has been the result of efforts to reduce health care costs. That is why it is imperative that caregivers are adequately trained to take on this role and that they are recognized as an important member of the health care team.

Although a number of innovative programs have been developed to address this particular need, these programs must be expanded. In addition, public and private insurance plans and managed care plans should offer benefits and services to train and support caregivers for their role on the health care team. Some have suggested that health care providers be reimbursed for such training and counseling services. Others have suggested that caregiving issues should become part of the medical and nursing school curriculum. We must act quickly to address this issue, because the need is overwhelming as cost containment strategies are implemented and as medical technologies grow more complex.

The second area is the need to provide support to meet the day-to-day, long-term care needs of the care recipient. More attention historically has been paid to the traditional issues relating to caregiving such as respite care and support groups. However, as this informal health care system grows, more programs and new approaches are needed.

Many caregiver support services are provided by local chapters of national voluntary health agencies, such as the Alzheimer's Association, or by community hospitals. These services may range from adult day care, to support groups, to training, to information and referral services. But many of these programs serve only a very small number of families due to limitations on resources and/or restrictions on eligibility. It is important that public policies seek to expand these types of local, community-based programs so more individuals can be served and future needs be met.

Currently, state governments, through their respective state agencies on aging and Medicaid agencies, administer most home- and community-based services for people with chronic diseases and/or disabilities. Typically the states have been leaders in developing strategies to provide more appropriate, integrated, and flexible services to meet long-term care needs and to identify methods to control costs. Experience has demonstrated that providing flexibility, typically through the Medicaid waiver process, is the best way to meet the diverse needs of individuals and communities. This flexibility requires a new, different federal role, largely one of partnership with the states in designing and managing programs. But I must stress that the federal government must provide the necessary leadership in this area.

Work and family demands often conflict with caregiving responsibilities. To maintain both work and caregiving roles, caregivers identify work schedule flexibility and information about community services for those with chronic diseases and/or disabilities as the most useful services employers can offer. These types of benefits are not only humane, but good business and should be viewed by employers as recruitment and retention tools.

In 1993, Congress passed the Family Medical Leave Act, which offered working caregivers an option of 12 weeks of unpaid leave to take care of a new baby or ill family member. We have seen the benefits of this policy and should consider expanding it to include employers with 50 or fewer employees and also to include definitions of family member as more than just children, spouse, and parents. The primary caregiver in many instances may be a granddaughter, niece, or daughter-in-law, relationships not currently covered by the Family and Medical Leave Act. I must add a caveat, however, to my remarks about the Family and Medical Leave Act. Studies have shown that few people utilize the Family Medical Leave Act for caregiving purposes, so we should not rely solely on this program to address caregiving needs in the workplace.

Finally, the Public Policy that will most support family caregivers is a policy that protects families against overwhelming long-term care costs. We must design various income supports to address the financial needs and insecurities of long-term care. One way to protect against the cost of long-term care is through affordable, private long-term care insurance. Public policies should encourage individuals to purchase long-term care insurance and employers should be encouraged to offer group long-term care insurance. However, I must stress that access to long-term care insurance does not address current or near-term challenges, since most people today in need of long-term care cannot afford to buy policies due to their age or medical status.

Some states have developed very targeted programs to address the different income needs of caregivers and different types of individuals providing caregiving. For example, some states provide a monthly cash benefit to the older and disabled person who, in turn, may choose to pay any person, including relatives and friends, to provide in-home care, such as assistance with activities of daily living.

Similarly, other states have looked at the unique needs of younger people who require long-term care services. Studies have shown that younger people frequently desire a level of independence often not desired by older care recipients. A four-state demonstration program will begin shortly in New York, New Jersey, Florida, and Arkansas to provide all people with long-term care needs with a cash benefit so they can seek out the programs they believe will best meet their needs. Enabling them to exercise their independence may result in better outcomes, both physically and emotionally.

Other state programs reimburse caregivers up to a certain amount for respite care and related services and for consumable items, such as "Depends." Medicaid reimbursement for consumable items is available when an individual is in a nursing home, but typically not available when care is provided at home. A few states even provide a one-time grant for home modifications and health care devices.

I must note that the government alone should not be expected to support and sustain the caregiving system. The entire health care community, including the for-profit and not-for-profit sectors, must work together, with government, to address this pressing issue. To that end, in December the National Health Council, with the National Family Caregivers Association, National Alliance for Caregiving and other Council members and nonmember organizations, will hold a Consensus Development Conference on Caregiving. We will bring together representatives of all the stakeholders dealing with this important issue. The goal of the conference is to develop consensus around, and set in motion, a series of concrete

steps -- an action plan -- that can be achieved within the next three years to address the key issues facing family caregivers, with the ultimate objective of better integrating the family caregiver into the formal health care system.

I look forward to working with you and the members of the Committee on this critical issue. Thank you for the opportunity to share my views with you today.